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THE PARK RIDGE CENTER

# Bulletin

JULY/AUGUST 2000



Children's Rights &

Health Care



## Bulletin

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The Park Ridge Center explores and enhances the interaction of health, faith, and ethics through research, education, and consultation to improve the lives of individuals and communities.

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# Society, Parents and Children, and Religion

david B McCURDY

Observers have remarked on the irony that a society so sensitive to the question of aborting unborn life is also a society that demonstrates surprisingly little regard for children.

This observation points both to society's ambivalence toward children and a corresponding ambiguity in the relationship between children and society.

In the medical arena, a presumed obligation to safeguard children's welfare is taken with utmost seriousness. Joel Frader describes how parents are not granted complete authority to determine what is best for their children. Parents who are Jehovah's Witnesses, for example, are seldom permitted to refuse blood transfusions for their children when life is at stake.

In the case of child immunizations, societal mandates reflect a public health concern for children. Robert Wolfe and Lisa Sharp point out that parents who would refuse vaccinations for their own children create a perceived risk to other children: the risk of exposure to disease—a risk that, from a public health perspective, those parents may not legitimately impose. There is a clear sense that the prerogatives of some parents must be abridged in order to protect children other than their own.

Yet the flourishing of children is not a consistent social priority. Society assumes

considerable responsibility for averting or removing significant harms to children, but less responsibility for children's well-being. This responsibility has been seen primarily as the obligation of parents, not society at large. The religious traditions would remind us that avoiding responsibility for children's well-being, their health in a broad sense, is not optional. They press us not to be content with the status quo, to keep striving at ways to create society in which parents and children receive optimal social support and parents are helped to foster their children's flourishing.

Most of our societal and parental concern about children is aimed at figuring out what we adults must do for our children. Only recently, as Frader points out, have we begun to acknowledge that there really are "mature" minors who, both ethically and legally, should be permitted to make health care decisions on their own behalf. We have been less able, or perhaps willing, to see that children have wisdom, indeed spiritual insight, from which we may learn. Diane Komp suggests that the religious traditions may be way ahead of us. They recognized long ago that children have something to teach. And what they teach is not knowledge as "content" but lived wisdom as a way of being in the world. It is a wisdom of the heart as well as the mind, and is easily missed unless we listen carefully. ■

# Younger Yet Wiser

*Courts allow mature minors medical autonomy*

joel FRADER

In the late 1980s a seventeen-year-old girl, known to the courts as E.G., developed acute nonlymphocytic leukemia.

Like her mother, E.G. was a Jehovah's Witness. She and her mother agreed to treat the leukemia with chemotherapy but they refused all blood products—E.G.'s doctors felt she would need transfusions to counter the effects of the drugs given to treat the leukemia. When she refused the blood her doctors reported the case to an Illinois child protective agency, which filed a petition in juvenile court alleging child neglect. A trial court agreed with the state agency and appointed a guardian to authorize transfusions for E.G., who appealed the decision. The appellate court found the adolescent to be a "mature minor" who could refuse transfusions on religious grounds, but agreed with the trial court that E.G.'s mother was neglectful. When the Illinois Supreme Court reviewed the decision, they agreed that E.G., having been judged adequately mature, could refuse blood products and found that her mother's acquiescing to the decision did not constitute neglect.

The case raises some important issues regarding minors, religion, and health care. While many children profess a belief



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in God, it can be difficult to determine the extent to which their expressions represent mirroring of their parents' beliefs. At what point in human development does an individual possess the requisite understanding and maturity to make a meaningful choice about a faith tradition? Are the standards used to measure an adolescent's readiness to drive a car, vote, or enter into a contract adequate to judge his or her acceptance of God? How should we understand a child, or for that matter the child's parents, that accepts some aspects of allopathic medical care but rejects others on religious grounds? Some physicians argue that such picking and choosing is inherently irrational, and therefore evidence of an inability to make reasonable medical decisions.

Jehovah's Witnesses reject cellular blood products based on several passages in the Old and New Testaments. Acceptance of

noncellular elements of blood (plasma, immune globulin, other blood products that do not contain red or white blood cells or platelets) is left up to the individual's conscience. Similarly, the group does not prohibit solid organ transplantation, despite the fact that the transplanted organs may contain residual blood from the organ donor. Witnesses accept other elements of modern medical treatment, relying on their interpretation of scripture solely for the prohibition of selected blood products.

The selective rejection of limited and specific aspects of allopathic medicine by Witnesses disturbs some physicians. These doctors sometimes have an easier time understanding, if not accepting, the more thoroughgoing rebuff of modern medical treatment by Christian Scientists and others. In the last half of the twentieth century U.S. courts have generally upheld the right

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of adult Witnesses to refuse blood, even in life-threatening circumstances. But the picture has been quite different with regard to minors. On the theory that children of Witnesses should have the opportunity to grow up and make their own decisions whether to accept or reject the views of their parents, U.S. courts routinely reject Witnesses' efforts to prevent transfusions when physicians claim they are necessary to sustain a child's life. In the case of E.G., the Illinois Supreme Court, told the legal system and physicians to slow down and think about their typically reflexive overriding of the views of minors who accept the Jehovah's Witnesses doctrine.

The Court's decision reflected a trend in U.S. law toward recognizing the arbitrariness of age as a criterion for determining decision making capability. Some children have the intellectual capacity and maturity to make important decisions, even life and death ones, well before their eighteenth birthdays. At the same time, many over the age of eighteen, despite their legal entitlements, lack the skills necessary to make good judgments—whether about medical care, employment, handling their finances, or sexual activity. The Illinois Supreme Court recognized a legal notion other courts and some state legislatures had increasingly embraced since the 1960s, the doctrine of the mature minor. The Court said that clinicians, the state (e.g., child protective agencies), and lower courts should examine the particular abilities of minors to make specific decisions. In some cases, including that of E.G., a minor may be deemed mature enough to embrace religious faith even when the beliefs have grave implications for his or her survival.

Not everyone agrees that what happened in the case of E.G. is a good thing. Advocates such as Scott, Reppucci, and Woolard, authors of a 1995 paper on adolescent decision making, feel that such court decisions represent bad public policy. They argue that adolescents routinely act in ways suggesting a systematic inca-

capacity to make good choices. They cite studies showing adolescents 1) too easily influenced by others (peers, family members); 2) too tolerant of risks; and 3) too focused on the short-term consequences of their actions to make reasonable, independent decisions. According to this view, with just a few more years of seasoning most will behave quite differently from the way they act within their teenage years. Presumably this view applies to matters religious as well as to those secular.

What is the pastoral counselor, physician, or ethics consultant to make of all this? Surely we cannot equate religious sincerity, or even degree of devotion to religious practices and principles, with mature acceptance of faith. Whatever it means fully to adopt a religious tradition into one's heart and soul, simply counting how often a young person attends religious services or how well she or he can recite religious teaching does not fully address the question of the maturity of the belief. We have no touchstone for assessing the depth of religious conviction. Should we then handle religious refusals of treatment the same way we deal with other treatment refusals, relying on the same measures ordinarily used to assess decision-making capacity?

In the United States, law and ethics strongly support personal autonomy for adults. Clinical and legal assessments of capacity or competency do not rely on an assessment of the results of a patient's thinking. If the individual has the required information, understands what it means, appreciates the consequences of choosing among alternatives, and makes a decision without undue influence from others, our system does not require a rational choice. A fifty-something professor can choose not to have surgery for coronary artery disease, against the advice of her physicians, even if her reason is her discomfort with others looking at her naked body on the operating table. She can reject recommended therapy for cancer in favor of a trip to Tahiti, even if everyone else thinks she is making a "crazy" choice.

However, we have a different standard for decisions about minors. We do require that minors make rational choices or that their legal guardians, usually their parents, do so. We respect the choice of a teenager to cooperate with recommended treatment and expect that his or her parents will agree to the treatment on the minor's behalf. The decisions have to be rational or reasonable, in the eyes of clinicians and, typically, the state. Minors should not have the opportunity to make the irrational decisions their somewhat older friends or siblings can.

But perhaps we should make exceptions from time to time. While we should presume teenagers cannot make good life or death medical choices, some ought to have the chance to win enough respect from clinicians or judges to make precisely those choices. In their cases, it should not matter whether the basis for the choice involves spiritual beliefs or preferences based on prior experience.

Ambivalence about this matter seems inevitable. We want the states to remain distant from family functioning, but we also have a hard time accepting religious perspectives on the meaning of life and death when they deviate too far from mainstream secular or religious views. For those whose religion does not fear death, the state's intervention in the lives of children—even when intelligent adolescents embrace the faith—must seem cruel indeed. ■

# Leave No Child Behind

*What you can do to build a movement*

marian WRIGHT EDELMAN

It's time for a revolution in values and political priorities which we can and must accomplish if we *believe* we can; if we speak out passionately and unceasingly; and if we organize effectively for our children's sakes.

## **Step 1. Seize this historic and prosperous moment to provide our children with an alternative vision for living.**

Now is the time to get America to make a positive rather than negative compact with our children to ensure every child receives health care; to give children the chance to get ready for and learn in school; to end child poverty and hunger and homelessness; to protect children from gun violence, abuse, and neglect; and to provide children attentive, caring adults and mentors in non-school hours. And now is the time to give our children a sense of being valued by structuring family and community life and public policies with the needs of children as the first rather than last concern. In every sphere of our personal, community, and

national life we adults should ask ourselves three questions:

1. Would we want our child or grandchild or any child to see, know about, or emulate our conduct?
2. Will our actions or inactions make it easier or harder for children to grow up healthier, safer, and compassionate?
3. Will our actions make it easier or harder for parents to raise healthy children and to balance work and family responsibilities?

## **Step 2. Strengthen women's voices, values, and power in every sphere and crucial institution of American life.**

Every federal and state senator and representative and every governor should be adopted by a well-informed, well-organized group of determined women and their allies with a focused agenda for children. And women when they gain power must not seek to emulate the values and actions of many men in power but bring a new moral dimension drawn from the insight of their struggles and marginality. We must insist and work together on one or two groundbreaking investments and protections for children each year until the whole of our children's needs are met and our children's compact is realized. Single-minded focus and message, clear policy goals, persistence, and organized clout are the recipe for success for children.

## **Step 3. Vote for and with chil-**

## **dren and monitor how those you vote for protect children.**

Be a good citizen and citizen-mentor for your children and grandchildren. Every parent and grandparent, aunt and uncle should get out and vote and take your child, grandchild, niece, nephew, or a neighbor's child with you. Let's teach children by example the importance of voting in a democracy. And let's vote for children. Women who waited 143 years for the right to exercise our citizenship and Blacks who gained the franchise only after decades of struggle have a special responsibility to honor the sacrificial efforts of our ancestors. That only 55.5 percent of women and 50.7 of Blacks and only 30 percent of 7.3 million eligible young voters age 18-19 (who did not have to wait or struggle at all) voted in the last election is a wasted opportunity. What if we all voted for health insurance coverage for all parents and children in 2000?

## **Step 4. Hold governors, state legislators, county and city officials in every state accountable for protecting children in this era of devolution.**

Children's Defense Fund will release an annual report card on how well states are investing in and protecting children to inform and help you monitor your state's performance for children. You will see how well your state is serving children in a number of key areas like implementation of the Children's Health Insurance Program and Medicaid and how your state compares to other states. Too many states

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Marian Wright Edelman is the founder and president of the Children's Defense Fund. Her most recent book is *Lanterns: A Memoir of Mentors*, published in 1999.

are dragging their feet, doing poor outreach, erecting bureaucratic hurdles which parents and children cannot jump over; are not investing significant amounts of state tobacco settlement monies on children; are not using surplus and budget dollars to help children; or are waiting on federal hand-outs rather than investing enough of their own dollars on Head Start, child care, and health for their state's children. If states, counties, and cities made a commitment to reach out to and see that every child and family received available benefits, millions of children could escape hunger, homelessness, and poverty.

#### **Step 5. Counter the common excuses of those who neglect children's needs.**

These excuses include the following: (1) "It costs too much to eliminate child poverty." Yet the moral costs to America's soul and ideals of not eliminating child poverty is beyond measure and the economic costs of permitting 13.5 million children to remain poor exceed the costs of its elimination. Economists estimate \$130 billion in lost productivity for every year we let one in five children live in poverty. (2) "It is not the right time." It is always the right time to do the right thing. During economic downturns, children should not be the first to suffer huge budget cuts nor should they be the last to benefit during economic upturns. (3) "Nothing works." Many things work which we simply do not provide to all eligible children. Less than one half of eligible children get a Head Start; only 49% of poor children eligible for food stamps which stave off hunger get them; wonderful model schools abound; few if any whole school systems educate all their children well. (4) "Children are not my responsibility. They are their parents' responsibility." Parents should do everything they can to raise and support their children but if they work and their employer does not provide health coverage, their children should not be denied health care. (5) "The poor should not

have babies they cannot support." No one should have children they can't support emotionally as well as financially. Who among us has the right to decide who should bear a child or blame a child for parents she or he did not choose? My Bible tells me to help rather than judge or blame the poor or the non-poor who neglect their children. And nowhere does it tell me to blame or punish infants and toddlers and young children for being hungry or abused. (6) "It's class warfare to talk about redistributing income to the poor." No one raises this issue as government policies have historically (and currently) redistributed income from the middle class and poor to the rich through tax breaks and subsidies for wealthy corporations and individuals. Who should have the first call on society's resources: them who need them most or those who have the most?

#### **Step 6. Never lose hope and faith or doubt that change is possible.**

American slavery and segregation ended because enough people said enough. Wars may never stop but we must not stop trying to eliminate them and speaking out against violence or believing that we can build a world without war for our children. Racism may raise its ugly head after an era setting God's child against God's child, but we must never condone it, praise it, glorify it, spread it, or cease trying to rid our minds and hearts and communities of its debilitating virus. The poor may have always been with us but we can decrease their numbers and their sufferings rather than ignore or treat them unfairly in our public policies and private conduct. ■

## **Call for Papers**

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SECOND OPINION is a peer-reviewed journal published quarterly by the Park Ridge Center for the Study of Health, Faith, and Ethics. Its focus is the intersection of health and medicine, ethics, and religion. A diverse readership includes clinicians, ethicists, policy makers, theologians, chaplains, medical humanities and religious scholars, journalists, and educated general readers. Original scholarly essays are invited, as are features dealing with a wide range of issues in the medical humanities: first-person narratives, fiction, poetry, art, personal perspectives, debate and commentary, and preliminary reports of works in progress. Issues of special interest include spirituality and health, the role of religion and faith-based organizations in health care, perspectives of specific religious traditions on health issues, ethical and religious challenges of science and technology in general and of the postgenomic era in particular, aging, care and coping at the end of life, inequality in health care, public and global health, and social justice.

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# Looks Great on Paper

*Can a state deliver health care for poor children?*

**thomas YATES**

**M**any poor children receive medical care because of the Medicaid program, created in 1965 as part of President Lyndon Johnson's Great Society.

On paper, Medicaid looks like a dream program. Services eligible for coverage are extensive: well child care, immunizations, and all medically necessary treatment. In Illinois most doctors and medical institutions have registered with the program. Finally, far in advance of most other health care plans, Medicaid applicants and recipients have the right to appeal, receive hearings, and sue to challenge both the denial of coverage and the denial of services and care.

Detractors observe that what's on paper does not provide an accurate description of how the program operates on the ground. Many eligible children are denied coverage because of the program's bureaucracy, and many others cannot find doctors to treat them.

While Medicaid has been criticized as too extensive and too expensive by some, the fact is that it is the only program that pays for basic health care for poor children. In Illinois, over 700,000 children are enrolled in Medicaid and depend on it for



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access to health care. In Cook County, over 70% of the families with incomes below 133% of the federal poverty level have at least one family member enrolled.

Medicaid is a joint federal-state program. In return for federal financing—50 cents out of each dollar spent—Illinois agrees to operate the state program under broad federal parameters. However, states are given great latitude.

Most parents in Illinois who seek Medicaid coverage for their children apply by going to the local Illinois Department of Human Services office. If the Department's case workers find that the children are eligible for coverage, the parents receive a medical card. Presented at the doctor's office, clinic, or hospital when

medical treatment is sought, the card serves as a payment voucher. Although the program is required to reimburse providers for all necessary medical services needed by children, the irony is that many doctors will not accept children as patients who are on Medicaid. Medicaid reimbursement rates lag far behind what is paid for children's services by private insurers. And, when Illinois tax collections lagged in the past, doctors often waited months to be paid.

The children's Medicaid program rests on three legs: eligibility for services, services covered, and available providers. Each is crucial in the delivery of health care services to children.

Children qualify for Medicaid in two

Thomas Yates is an attorney at the SSI Coalition for a Responsible Safety Net, a nonprofit agency that works to protect and improve programs that assist low-income elderly and persons with disabilities.



different ways. Some are in families receiving cash benefits from Illinois under the Temporary Assistance for Needy Families (TANF) program. Children in families with incomes up to 185% of the federal poverty level also qualify. In 2000 an Illinois family of four can qualify for Medicaid coverage for their children if family income is less than \$2629 a month.

However, in assessing family income, no consideration is given to health care expenses. A family of four with monthly income of \$2600 will qualify for coverage for their two children, while a family of four with monthly income of \$2700 will not. A child with a chronic health condition that requires frequent medical care generally will not qualify for Medicaid—regardless of the total cost of medical expenses—if family income is too high. As a result, many families in Illinois who do not have access to health insurance through other avenues, such as employment, must limit family monthly income to ensure that their children can continue to qualify for Medicaid coverage.

Some children do not receive benefits as a result of problems within the bureaucracy. For example, welfare computers automatically terminated Medicaid for children in families ending TANF even though they continued to be eligible. Other families were improperly denied coverage.

In other areas, however, Illinois acted wisely. Despite federal cutbacks for immigrants, Illinois agreed to provide Medicaid to many immigrant children who would otherwise be ineligible. And Illinois has moved forcefully in the past few months to identify and enroll children in families whose incomes make them eligible. Other agencies, including the Chicago Board of Education help to identify children who may be eligible for coverage. The goal is to locate and enroll all children who are eligible, ensuring that no child goes without health care because of a family's inability to pay.

Medicaid is unique in that it is required, in the words of the Illinois authorizing

statute, to cover all medically necessary care and treatment for children.

Federal Medicaid rules have long required states to reimburse medical providers for preventive care and immunizations. Under the Early and Periodic Screening, Diagnosis, and Treatment program, Illinois is responsible for providing medical check-ups, vision, hearing, and dental services as well as necessary diagnostic and treatment services to all Medicaid-eligible children from birth through age twenty.

But the data shows that Illinois, like most states, has not done well in ensuring that children enrolled in Medicaid receive preventive health care. State Medicaid data, provided in pending litigation, suggests that less than half the eligible children from birth to two years of age received the screening examinations found essential by the American Academy of Pediatrics. Data for immunizations likewise shows that many children do not receive necessary immunizations until they enter school at age five.

The great unknown in the Medicaid program is whether there is a sufficient number of providers to meet the health care needs of children in Illinois. Health care providers who treat these children are varied, from doctors in their own offices to hospitals and neighborhood health clinics. For the most part these medical providers may choose whether or not to serve a child on Medicaid. While most pediatricians and family practitioners in Illinois treat some children enrolled in Medicaid, the majority of these patients of are treated by a relatively small number of doctors.

While doctors are not required to accept patients enrolled in the program, Illinois is required to ensure that children on Medicaid have adequate access to health care. The federal statute provides that states must reimburse at rates sufficient to ensure that the number of health care providers available to children on Medicaid is the same as available to the population in general. There is no reliable

data that tracks whether this requirement is being met, but Medicaid reimbursement rates are much lower than those paid by private insurers.

At present, Medicaid is the only viable system in place to provide health care financing for low-income children in Illinois. However, much remains to be done to ensure that these children receive adequate preventive care and treatment.

The state must work to ensure that children whose families lose cash assistance under TANF continue to receive Medicaid. And it must investigate imaginative ways to provide Medicaid services to families who have medical costs that drive their income below 185% of the federal poverty level.

Illinois also faces great challenges in ensuring that children enrolled in Medicaid receive the preventive services and immunizations they need—and in a timely fashion. Finally, Illinois must address the issue of medical provider access squarely. Recent expansions in eligibility will be of little consequence if these children, once enrolled, cannot find doctors to treat them. ■

# Acts of Faith

## *Religion, medicine, and the anti-vaccination movement*

robert M WOLFE and lisa K SHARP

Since Edward Jenner's discovery of the smallpox vaccine in 1798, immunization against diseases has become a multi-million dollar industry.

Most children in the U.S. will get at least twenty-one vaccinations before they start first grade. Public health officials argue this is one of the most effective medical interventions we have to prevent disease. So why are physicians faced with increasing numbers of parents who refuse to immunize their children?

This refusal is frustrating and perplexing for many physicians. Parents have many reasons: vaccine safety issues, concerns about side effects, moral concerns about the use of fetal tissue in some vaccines, or the belief that natural immunity can be fostered. Consider the case of a young couple who decided, after great deliberation, not to vaccinate their six-month-old son. They have researched the pros and cons and have discussed the matter with their religious community. The primary care physician strongly disagrees with the decision. The parents

explain that they are concerned about possible side effects of vaccination and about some of the ingredients used in vaccinations. The physician assures them that the benefit far outweighs any small risk. They express their unwillingness to have their baby injected with foreign substances, and they explain their belief that God will take care of their son if they are faithful. The physician explains that God had a hand in the discovery of the vaccinations and that their child will be in danger should they decline. The parents stand firm in their conviction. Both parties feel completely justified in their decision, yet frustrated by the lack of understanding. Such clinical encounters place the doctor-patient relationship at risk.

The recent withdrawal of the Rotavirus vaccine due to worries about side effects and the controversy over possible toxicity from thimerosal, a mercury-containing preservative used in vaccines, has raised concerns. In the past year several Congressional hearings have been held on this subject. Danielle Burton Sarkine, whose infant daughter "almost died after a reaction to a hepatitis B vaccination" and whose fourteen-month-old son "was left autistic after receiving nine vaccines on one day," introduced her father, Committee Chairman Congressman Dan Burton. He spoke about exploring the connection between vaccines and brain and immune system dysfunction in children, particularly a suspected link between autism and the measles/mumps/rubella (MMR) vaccine. Such concerns are controversial in the medical establishment. In respected journals such as the *British Medical Jour-*

*nal* and the *Lancet*, heated discussions have flared about whether or not vaccination is related to a variety of ills such as autism, diabetes, and Crohn's disease.

To some extent, increased availability of information is responsible for these concerns. Anti-vaccination web sites have proliferated. A survey by Cyber Dialogue, an internet research firm, found that over the last twelve months 7.5 million U.S. adults began using the Internet to find health and medical information. This represents a 43% rate of increase, nearly double the Internet's 22% overall rate of growth last year. Today, 35% of all U.S. adults are online and of these, 38% have used the Internet to gather health and medical information during the last twelve months. In 2000, more than 33.5 million adults are expected to seek health information online. Parents doing an Internet search for information about vaccinations can easily find sites where the dangers of vaccination are presented graphically and emotionally. (See the National Vaccine Information Center web site at <http://www.909shot.com/>.)

Biomedicine views immunizations as a means of protecting the individual and society against potentially life-threatening illness. The risks associated with immunizations are considered extremely low and must be weighed against the overwhelming benefit imparted by immunity. Refusing vaccinations is tantamount to a mortal sin within biomedicine and is viewed by some as a form of child abuse and neglect.

Richard Moskowitz, M.D., an opponent of vaccination, writes:

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Vaccines have become sacraments of our faith in biotechnology in the sense that 1) their efficacy and safety are widely seen as self-evident and needing no further proof; 2) they are given automatically to everyone, by force if necessary, but always in the name of the public good; and 3) they ritually initiate our loyal participation in the medical enterprise as a whole. They celebrate our right and power as a civilization to manipulate biological processes ad libitum [as desired] and for profit, without undue concern for or even any explicit concept of the total health of the populations about to be subjected to them.

The risk-benefit ratio shifts when God enters the equation. A basic tenet of Christianity and Judaism holds that the body is a sacred temple of God. Injecting toxic particles into the body to produce an artificial immune reaction is seen by some religious persons as opposed to natural methods of promoting health. This view was a major source of the opposition to smallpox vaccination in the 1800's. One opponent described it as "an attempt to swindle Nature." Similarly, the benefit of immunity against disease becomes irrelevant for those who believe that faith in God protects the individual from illness. Refusing immunizations may therefore be seen as an act of faith.

The tension between vaccination and religious belief is not new. The British Vaccination Act of 1853 mandated universal vaccination and imposed fines and jail sentences for refusal. As a result, anti-vaccination leagues sprang up to oppose and abolish mandatory vaccination. An example of the almost religious quality of the opposition can be seen in this excerpt from an 1878 newsletter of the Anti-Compulsory Vaccination Society:

*A word for the unfaithful*

As a rule, those who hate vaccination itself are yet too mean-souled to protect their children if thereby there be any danger of fine or imprisonment ...to

have to battle with the vaccination tyranny is hard; but...though the way is longer than we would fain see it, we must just "foot it boldly, strong or weary," and take courage in the assurance that "in due time we shall reap if we faint not."

Opposition may also arise from the perception that society is spiritually insensitive. Many spiritually-oriented people find the modern, information-glutted electronic world, with its biomechanical model of reality, to be overwhelming. They reject the perceived impersonality and homogeneity of the allopathic medical approach and its relative disregard of spiritual and physical integration. Thus, exemptors often seek healers whose model of medicine is based on a top-down approach; that is, the healer first tries to orient himself to the patient's world-view before beginning treatment. By contrast, modern medicine is often bottom-up: the symptom and its cause at the molecular level is the focus, and the big picture is relegated to a lesser significance. For spiritually oriented healers, any treatment is individualized—not in the sense that the dose is adjusted for weight, but in the sense that different treatments may be used for different patients with similar symptoms. Thus, vaccination is often rejected as being "one size fits all." Homeopathy, with its emphasis on individualized, non-toxic treatments, is often preferred for this reason.

The use of aborted fetal tissue is another reason vaccines are rejected. Some current chickenpox and rubella vaccines originated from lung tissue of aborted fetuses. The Catholic Church has justified the use of these cell cultures, arguing that the immoral act which procured the tissues is "complete and sufficiently remote" from the present use of the tissues, so that whoever uses the vaccine today is not morally complicit in the original abortion. They also argue that the present use does not create grounds for objection because the cells constitute "independent,

possibly different, life." These points have been forcibly challenged by other Catholics. One anti-abortion writer, Steven Kellmeyer, argues:

It is irrelevant that the abortion is a one-time long-since completed event. A rape-murder committed in 1961 is also a one-time long-since completed event, but it is still immoral to buy the film of the event for one's own enjoyment.

A wide variety of spiritual and moral concerns motivate parents to reject vaccination. Does the parents' refusal put the child at risk? This winter an outbreak of measles in the Netherlands among religious exemptors led to 2961 measles cases, with 68 hospitalizations, including three measles-related deaths. Some argue that vaccination would have prevented this tragedy, while others argue that the vaccination would have caused more tragedy. Indeed, a comparison of two groups of parents, one favoring and the other opposing vaccination, found that when given a chart of data about the risks of diphtheria vs. the diphtheria vaccine, their views became more stratified: those who were pro-vaccine were more in favor of vaccination, and anti-vaccinators were more opposed.

Perhaps we should put ourselves in the child's position and ask ourselves: 1) would we prefer a greater or lesser chance of death, and 2) would it matter, from the child's point of view, whether this came about by the parents' act, such as a vaccine-related event, or by omission, in the event of disease from failure to vaccinate. One study showed that according to this "Golden Rule" argument, exemptor parents were more likely to vaccinate their child.

Vaccination is unique among government mandates in the modern era, requiring individuals to accept a medicine or medicinal agent into their body. Opposition began with the first vaccinations, has not ceased, and probably never will. ■

# In a Child's Eyes

*A young cancer patient shines a spiritual light*

**diane KOMP**

*"Nothing is so beautiful as a child going to sleep while he is saying his prayers, says God. I tell you nothing is so beautiful in the world."*

—Charles Péguy, *Basic Verities*

**J**esus said that unless we adopt the viewpoint of a little child, we will never enter the kingdom of heaven.

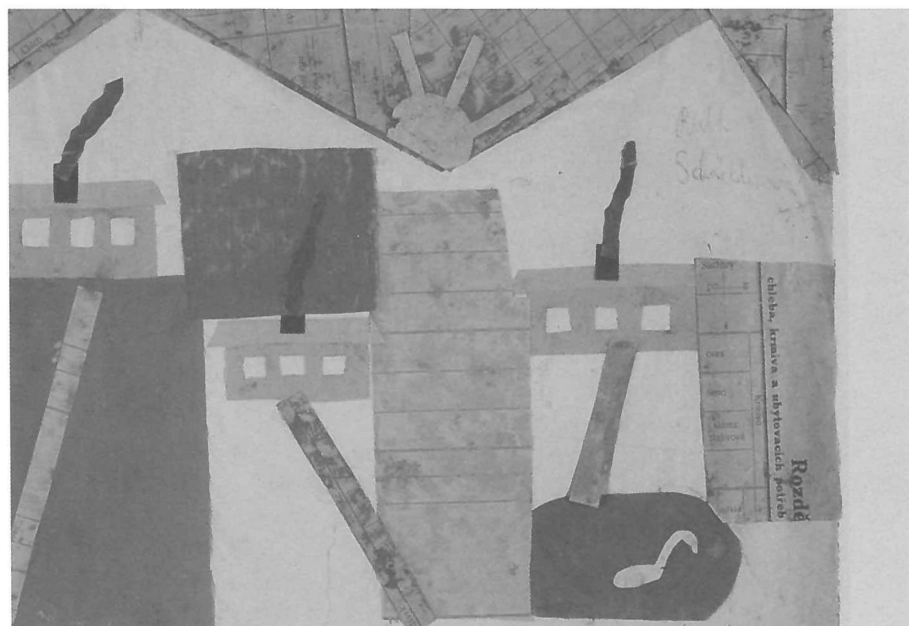
I've often wondered then why adults, not children, are in charge of religious education. And at my own spiritual crossroads, I returned to faith when I learned to stop, look, and listen to what children have to say.

Stop, look, and listen—advice we often give to children for their own safety. When it comes to their spiritual formation, then, we should take our own excellent advice. Otherwise we may project our own adult fears and ignorance onto the little ones.

## Stop

One thing is certain about serious illness in children: it is a show-stopper for adults. For a change, we are speechless. We run out of wise things to say, as Nancy and Brad did the day they invited me to visit with their dying son.

In the months Scotty had been treated



Jewish Museum/Prague

for cancer, they had raced around looking for a cure. Their task, as they saw it, was to find the right doctor and the right hospital for their son. Not once on that quest did they stop and consider the spiritual meaning of their pilgrimage, or what their thirteen-year-old son thought about a life-threatening illness. When they had exhausted their share of medical non-miracles, they came home to where they had begun with new questions. How do we talk to our child about dying?

On that gray late winter day we stood still together. "You know," I told them, "if I had one wish that could be granted, I wouldn't ask for beauty, or wealth, or power, or even for intelligence. I would ask for wisdom."

They turned from staring out the window. I had put their thoughts into words.

It isn't in the nature of adults to stop

when we're fearful. For us it's a time for fight and/or flight. In fact, it's counterintuitive for the parent of a child at risk to do nothing. Good parents take responsibility for the welfare of their children. But there is something holy and healthy about acknowledging that we are not God for our children. We are merely fellow pilgrims.

## Look

At Brad and Nancy's invitation, I joined them to visit Scotty. From a medical perspective, there was no question that he would die. His lungs were full of fluid. He was careful not to talk too much, lest it start him coughing. He would measure his words.

Scotty's parents had been attentive to his religious formation. In fact, they sent him to parochial school. But Brad and Nancy told me that they had no idea what

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Scotty thought about death. No one had told him directly that he was dying.

I have an image in my heart of a scene that happened in the X-ray department several days before my visit. Scotty's intern shared this story with me. As she passed him in the hallway, Dr. Sharon grinned at Scotty and yelled, "Give me high five!" As she brought her hand closer to his in this familiar pediatric salute, Scotty took her hand and drew her close.

"No," he said to his young doctor, "I want to hug you while I still can." There were tears in Sharon's eyes as she told me this story.

If you look at a dying child, you have two choices as to what you will see. Either you will see your fears spelled out in medical data and facts, or you will see an unquenchable spirit inviting you to draw near.

## Listen

"What do you write about?" Scotty asked me, careful not to cough.

"A long time ago," I told him, "I figured out that I didn't have all the answers to life's most important questions. I learned that when I listen to kids—kids like you—I get more sensible answers than I hear from most adults. So I listen to children's stories and I write them down."

"You know," he said, warming up his story, "not everything in science is true. And not everything in religion either."

"What is it in science that you have difficulty believing?" I asked him.

"Well, take the Big Bang theory, for instance," he replied.

"OK," I said. "What's your problem with the Big Bang theory?"

"They say that the world came about by accident. But when I look at the world and everything in it, I see a design and a plan. I could be wrong, but I doubt it."

Scotty folded his arms across his chest, firming up his position.

With science put squarely in its place, we moved on to his other area of doubt.

"What is it about religion that you

have trouble believing?" I asked him.

"Well, take David and Goliath, for instance."

"What, pray tell, is your problem with David and Goliath?" I asked him.

"Well, they say that Goliath was 8'4" tall, and there is nobody that tall," Scotty said firmly.

"I've seen some pretty tall basketball players in my time," I countered.

"Not that tall," he insisted.

I was losing the argument, so I got medical.

"There's this pituitary condition where you keep making more and more growth hormone, and you keep growing and growing and growing."

"Not that tall," Scotty said. His arms re-crossed his breast to hold his position tight. Then he became very quiet.

"You know," he said softly, "it's not the details that matter. It's the moral of the story."

I was speechless, and so was Nancy who was standing by the bedside wondering, "Is this my son talking?"

I thought about this boy, immersed in the terrifying world of high-tech medicine. Then I thought about David and Goliath. Just what was the moral of these stories, young Scotty's, young David's? Both stories are tales of little lads who would prevail against something that was unbelievably big. As big as Goliath. As big as death. But Scotty wasn't finished with me yet.

"Do you pray?" he asked me. Patients don't often ask their doctors this question!

"Yes, I do. Do you pray?" I wondered back at him.

"Every night," he retorted.

"Now that really interests me," I said. "And I need to learn a lot about prayer. Perhaps if you told me what you know about prayer, I might learn something helpful. Tell me how you pray."

"I start by saying a prayer," Scotty said, and started reciting a child's prayer from rote memory. "Now I lay me down to sleep. I pray the Lord my soul to keep."

As he looked up at those invisible but powerfully present words, Scotty started nodding as if he agreed with himself, agreed with what he had just read. "If I should die before I wake," his nodding became more vigorous, "I pray the Lord my soul to take." He was pleased with his words. "And then I pray for everyone I know."

"I tell you what, Scotty," I said. "I'll pray for you if you'll pray for me." Scotty smiled softly, and then he said, "I've already been praying for you. Every night I pray for all the doctors and nurses on the team."

The most precious lessons in spiritual formation I've learned have been from dying children. But Jesus was talking about all children when he said: "I tell you the truth, anyone who will not receive the kingdom of God like a little child will never enter it." I wonder what we might learn if we stopped, looked, and listened to all the children in our lives? Instead of saying, "Let me tell you about God," just once ask a child: "Tell me what you know about God." Even when we are up against something that is unbelievably big, we may enter a realm where we too are part of a grand design and a heavenly plan. ■

Excerpted from *Bedtime Snacks for the Soul: Meditations to Sweeten Your Dreams* to be published this fall by Zondervan. Used by the permission of the author.

# To Care and Protect

*Ethics and child welfare services*

**martha B HOLSTEIN**

**T**he journalist Clarence Page once observed that, in ten years, his “then three-year” old son would be a member of the most feared group in America—the black teenager.

And what if this teenager grew up in the streets? What if he went from foster home to foster home because he was hard to manage even at age seven or eight? Might he be one of those rampaging men who recently terrorized women in Central Park? Too often we hear of children killing children. Or being victimized by biological or foster parents.

There are the good stories, too. Of the loving foster parents who lead children from months of blind alleys. Or of the letter in the newspaper from the now-grown child who gratefully acknowledges his foster mother. Or of the teenager once strung out on drugs, but now ready to graduate from college despite having two babies while in high school. That’s the stuff of child welfare services—how to prevent the loss of a generation to the streets, to jail, or to the insecurities of occasional work and poor education? How to achieve maximum success with constrained resources? How to care for and protect the young when much of society devalues and discounts their mothers?

Whether the stories are of havoc in children’s lives or of quiet success, the Illinois Department of Children and Family Ser-

vices (DCFS), like comparable departments in every state, encounters it all. They do so with neither the staff, often very young and marginally trained, nor the resources to do the job. They are readily blamed for their failures but rarely noted for their achievements. Every day, child welfare agencies encounter ethical problems that challenge understandings of such concepts as informed consent, confidentiality, and appropriate boundaries between client and worker. Every day, the boundaries between investigation and service challenge case workers. Constrained by regulations and policy preferences, child welfare workers often have few treatment options. Some child welfare professionals suggest that all the regulatory constraints disempower people at the bottom and limit flexibility and creativity. Workers are often unable to recommend what they consider best for the child because of the requirements of laws or regulations. The law, for example, wants foster children to be reunited with their natural mothers as quickly as feasible, but case workers can rarely offer inner city mothers the effective drug treatment that would satisfy the conditions for reunification. Even after reunification, families lack continued support to keep children from being forced back into the system.

For the past two years, the Park Ridge Center and DCFS have collaborated in a pilot project exploring key ethical questions that arise in child welfare work. With limited options at their disposal, how can child welfare workers think about moral issues and moral conflict?

How can the department monitor the many private agencies now central to the child welfare system? How can workers with heavy caseloads take the time to reflect about the decision-shaping values they bring to each case? How can agencies and the department address structural and legislative issues while meeting their mandate to help children thrive? This mandate seems simple; in practice, agencies face overwhelming odds.

A twenty-two year-old case worker, to take one example, establishes a strong relationship with a seventeen-year-old mother, but uses poor judgment when she finds alcohol and signs of an unsupervised party in the client’s apartment. Her supervisor doesn’t catch up with this incident soon enough to use it as a teaching moment, so the relationship between case worker and ward is threatened. Is the case worker letting her sympathy cloud her judgment? How can judgment skills be taught to young workers without jeopardizing good relationships?

The pilot project, which will soon produce teaching videos, will seek funding to undertake the complex task of developing new knowledge, exploring the threats to ethical practice in child welfare services, and engaging in sustained ethical analysis of issues identified by child welfare workers, supervisors, and their critics. Child welfare services hold a sizeable warrant on the future of many troubled children. DCFS and the Center have learned much in the pilot phase of our work together. We look toward a richer and more extensive collaboration. ■

### *Transfusion Confusion*

The *London Times* recently ran an article claiming “Jehovah’s Witnesses are to be allowed to accept blood transfusions after an extraordinary U-turn by leaders of the controversial religion.” It went on to say that this decision was reached at a “secret meeting of the 12-member world governing body.”

In a statement issued the same day by the Jehovah’s Witnesses New York public affairs office, denomination officials dismissed these assertions. “The Bible commands Christians to ‘abstain...from blood.’ (Acts 15:20). Jehovah’s Witnesses...have consistently refused donor blood ever since transfusions began to be widely used in civilian medical practice in the 1940s, and this scriptural position has not changed.”

Ethicists are encouraging doctors to continue respecting the Witnesses’s desire to abstain from blood, while urging the *Times* to abstain from irresponsible reportage.

### *Nigeria’s Virtue Subsidy*

In a new twist on the world’s oldest profession, Nigerian prostitutes are being paid to give up the trade. Earlier this year the Nigerian state of Zamfara instituted *shari’ah*, strict Islamic criminal law. Penalties for prostitution under *shari’ah* include amputation and beheading. But *Reuters* reports that the state government would rather have prostitutes marry, and is offering cash incentives (25,000 naira, approximately \$240) to achieve that end. The money is intended to help them start small businesses.

### *Education or Evangelization?*

In an effort to foster spiritual health among sailors, crew members and officers of the aircraft carrier USS Carl Vinson were ordered to attend “Spiritual Matters,” a religious seminar. Jewish, Muslim, and Christian representatives spoke during the two-hour session, reported the *Seattle Times*. It was designed, according to the ship’s brass, to promote respect for other religions.

But some of the sailors complained that the session was “thinly disguised evangelizing,” that they were forced to attend against their will, and that it was a clear violation of their constitutional rights. “I had to listen to a man...tell me that I am a sinner, while they had guards posted at the door to keep me from leaving,” reported a petty officer third class. The sailors were not unhappy with the rabbi or the Muslim cleric, who explained basic tenets of their faiths and then took questions. But the Protestant pastor and

the Roman Catholic priest provoked controversy. Attendees characterized their presentations as “sermons” in which they quoted scripture, argued against tattoos, and lectured on sin.

Captain Bruce Clingan, the ship’s commanding officer, justified the initiative by saying that the Navy has recently recognized medical evidence suggesting faith can contribute to a person’s well-being. It is therefore the Navy’s prerogative, he said, to offer spiritual, as well as physical and mental, training opportunities. He expressed hope that this would be the first of several. It is not known whether the Navy plans to invite pacifist denominations, such as Quakers and Tibetan Buddhists, to speak at future seminars.

—Kirston Fortune

THE ART in this issue has been used with permission of the Jewish Museum, Prague, and is available in their moving book *I Have Not Seen a Butterfly around Here*, a collection of children’s drawings and poems from Terezín concentration camp.

The piece on page 3 is by Ruzena Zentnerová (b. 3/26/33, d. 4/10/44).

The one on page 5 depicting a figure catching leaves is by Margit Ullrichová (b. 6/18/31, d. 10/16/44).

The collage of a village with a swan (lower right) on page 11 is by Ruth Schachterová (b. 8/24/30, d. 5/18/44).



# Health and Justice

*Do we need a new standard of sincerity?*

**martin E MARTY**

In the issue you have just read there have been a couple of items that could be described as “health, justice, and ethics” pieces.

This does not mean they are misfits, for a variety of reasons. For one, there is a huge overlap between faith and justice issues. For a second, we do not believe that the faith communities have any monopoly on talk about justice or the pursuit of it. And for a third, we believe that such communities and the general citizenry should draw on their separate and overlapping resources to make a common address to problems.

So a local story with national implications—which is what case studies and case stories tend to be—speaks of justice in respect to children in a particular state. Will the people of religious congregations and denominations, or those moved by faith-full impulses, show interest in the delivery of health care for poor children? Biblical traditions must recognize a mandate to do so.

Martha B. Holstein, meanwhile, has described a venture linking this center for health, faith, and ethics with a state agency which, in the nature of the case, cannot directly raise faith issues. She makes mention of the limitation of resources. The majority of the people in the state give some of their time, resources, and energy to religious institutions. Here again, the overlap between what these institutions offer and what the

public needs is significant.

What struck me as I re-read the articles in final form was this: as complex as secular justice matters are, everything gets more complex when one introduces faith questions. No state can limit and no church can confine the questions children ask in times of crisis—or the imagination they display as they set out to provide their own answers. It’s a touching vignette that Diane Komp has brought, and one likely to stay in the mind of anyone who wants to extend boundaries of empathy and care.

The problems that Robert M. Wolfe and Lisa K. Sharp, and then Joel Frader, raise cannot be easily addressed, to say nothing of being resolved. They will come up in countless new ways wherever the larger public interest and the particular religious sub-public collide in their interpretations and strategies.

It is easy to stand outside communities like those that oppose vaccination and view them as obstreperous at best, foolish in the middle, and destructive at their worst. What business have they jeopardizing *my* children’s, my community’s, and their children’s health by resisting long-approved measures such as universal vaccination, and doing so on legal grounds? Yet that ease appears mainly among those who either have had the luxury of not having their own beliefs challenged publicly or the burden of not having had beliefs strong enough for anyone to challenge. The insistent questioners of mainstream practice will not go away and will not be silenced. They will trouble majorities. The wise goal is to promote under-

standing that can at least see to it that the troubling is creative and not merely disruptive.

A similar case comes up with Jehovah’s Witnesses, troublemakers supreme on the civil, religious, and health fronts. In the end the Frader story is not, however, about Jehovah’s Witnesses but about young people, children, and both their rights and their discretion. The courts have not found clear and simple ways to address this kind of issue. For example, in respect to conscientious objection to military service, the Supreme Court within a half century moved from having the courts respect objections because of objector’s belief in a Supreme Being, to objections by those who are religious but without a Supreme Being, to objections of those who are not religious but hold to some philosophy that they adhere to with the fervor of conventional religionists. Some on and around the courts said that we had come now to sincerity tests. So it may be with both sincerity and maturity of discretion in health cases.

In any case, it is clear three times over in this issue that introducing faith onto the medical landscape may not solve anything. It does bring us closer to the real world as lived by real people, whose beliefs and problems do not fit into the standard texts. That is one reason we regularly issue a *Bulletin*. ■



THE PARK RIDGE CENTER

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